

THE MAINE COALITION TO FIGHT PROSTATE CANCER
WINTER NEWSLETTER
Volume #1, Issue #1

We here at the **Maine Coalition to Fight Prostate Cancer** are launching a newsletter. Our goal is to produce four issues a year on a seasonal basis. Each of them will provide prostate cancer survivors with links to reputable resources for prostate cancer information. We will provide notification about upcoming events of interest to prostate cancer survivors and their loved ones. We hope to have a physician column in each issue. As always, the Coalition welcomes suggestions and advice from members of the prostate cancer community. If you want information about a specific topic, please let us know by e-mailing mjervin@roadrunner.com. We encourage you to write to us about your prostate cancer journey. We can all learn from a personal testimonial.

For this first issue, we will deal with the basics. The Coalition was founded in 2005 by five men who had been diagnosed with prostate cancer. The mission of the Coalition is to “end the devastating impact of prostate cancer on men, their loved ones, and the State of Maine.” One goal is to inform men and their loved ones about treatments, research and other issues that survivors must face. The Coalition maintains a website at mcfpc.org that is a source of much valuable information. The Information Page of our website, containing information about prostate cancer, is a primer for newly diagnosed men and their loved ones. When hearing a diagnosis of cancer, the first reaction is often fear. Fear can lead us to make poor, snap decisions. We encourage all men and their loved ones to become educated about the disease. The Maine Coalition to Fight Prostate Cancer website is a good place to begin your educational journey.

On our mcfpc.org website, go to the **News Page**. Here we have a link to Urology Health (magazine.urologyhealth.org), published by the Urology Care Foundation. This magazine has timely articles, written in layman's language about prostate cancer and other urological problems. Once at the Urology Health site, click on the Patient Magazine tab located at the top of the page. You can read the articles online, or you can order the magazine free of charge.

We also have a link to **The Journal of the National Comprehensive Cancer Network** (jncn360.org). At the journal's website, click on the prostate cancer tab for scientific articles about prostate cancer, treatments, drugs, clinical trials, and a wealth of other related information.

On the **Resources Page** of the Coalition website (mcfpc.org) you will find information about cancer resource centers in Maine; organizations that can assist families with medical costs if they qualify; the locations of federally qualified low-cost health care centers in Maine; information about help with transportation costs while traveling for treatment; and information about lodging assistance while undergoing treatments away from home.

We have information for gay/bisexual men who have prostate cancer; information for women whose loved ones have prostate cancer; we have a book list; and a great deal of other information on the Information tab of our website. On the tab labeled **Prostate Cancer Networks**, we have the list of all prostate cancer support groups statewide. We are excited to report that two new groups will be starting up soon.

Another valuable tool that the Coalition has developed is the **One 2 One Confidential Program**. The program is for men who have issues but do not feel comfortable in a support group setting. Our trained

volunteers, all prostate cancer survivors themselves, have been there and can assist by listening, offering encouragement, sympathy, and non-medical suggestions. All conversations are private and confidential as the name implies. To reach a One 2 One Confidential Volunteer call 207-441-5374. After answering a few preliminary questions, you will be paired with a volunteer who has faced and overcome the same issues that led you to call.

UsTOO is another important resource. They are a national group that strives to provide awareness, resources and support to those affected by prostate cancer. Their website is www.ustoo.org. Click on the Education tab, scroll down to the Hot Sheet entry for a wealth of information. Each of the other UsTOO tabs is a source of valuable information. **ZERO – The End of Prostate Cancer** is another important source of information that you can find at zerocancer.org.

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Andrea Martelle, RN, OCN, ONN-CG from the Harold Alfond Center for Cancer Care has shared that **SpaceOAR** has been out for more than five years and the first five year quality of life results in a group of prostate cancer patients treated with a hydrogel spacer demonstrate excellent treatment tolerability, in particular regarding bowel problems. Patients receiving radiation at Maine General and Southern Maine Medical Center will be offered SpaceOAR before treatment. To read the study, go to ncbi.nlm.nih.gov/pubmed/28871986

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The Maine Coalition to Fight Prostate Cancer is pleased that **Moritz Hansen, MD, has contributed the following article for our newsletter.** Dr. Hansen received his medical degree from Columbia University School of Medicine in 1993. His internship was at Stanford University School of Medicine, Surgery in 1994. His residencies were at Stanford University School of Medicine, Surgery in 1995 and Stanford School of Medicine, Urology in 1999. Dr. Hansen has been with Maine Medical Center since 1999 and with Maine Medical Partners since 2008. The following was contributed by Dr. Hansen:

Prostate cancer represents a spectrum of disease that ranges from incidentally discovered slow-growing tumors with a low risk of clinical harm that may be managed without treatment, to intermediate-risk cancers that generally respond well to treatment, to high-risk cancers that pose a significant health threat and often require a variety of treatment strategies. For a man with newly diagnosed prostate cancer, the complexity of this disease poses the following questions: How do I understand my prostate cancer? How do I find support? And how can I access the care that I need? Fortunately for men and their families in Maine, educational and support resources, as well as world-class treatment, are readily available.

The Maine Annual Cancer Report (2018) suggests that Maine’s prostate cancer mortality rate is slightly higher than the national average. Though the reasons for this remain uncertain, a number of factors are likely involved. As the largest state in New England, Maine’s population is spread across a vast geographic expanse which presents a challenge to accessing information as well as to obtaining support and care. Furthermore, socioeconomic factors are strongly associated with cancer mortality in general, which is likely related to Maine’s higher prostate cancer mortality rate, particularly in rural and low-income communities.

Despite Maine’s overall higher prostate cancer mortality rate as compared to the national average, the American Cancer Society reports that Maine’s actual prostate cancer mortality rate has decreased by

approximately 30% since 2000. Though specific reasons for this mortality decrease remain uncertain, a number of factors are likely involved. The last two decades in Maine have been notable for a remarkable consolidation of patient education and support resources; some patients and family-initiated such as the Maine Coalition to Fight Prostate Cancer and, and hospital initiated. This has allowed men to access information and support soon after diagnosis to include individual One2-One support, support groups, web-based information and outcomes data, as well as through nurse navigation. In 2009 when Maine Medical Center established Maine's first prostate cancer navigation program, there were only a few such prostate cancer navigation programs in the United States.

Furthermore, Maine has also been a national leader in prostate cancer management and treatment at all risk levels of disease. For men with low-risk prostate cancer Maine was one to the earliest adopters of a formal active surveillance program, which currently includes multi-parametric prostate MRI fusion surveillance biopsies. For men with intermediate-risk disease, Maine has also been a national leader in prostate cancer surgery, radiation therapy, and treatment outcome research. When Maine's first robotic-assisted radical prostatectomy (RARP) was performed in 2003, the state joined New Hampshire and Connecticut as the first three states in New England to offer this technology. And for men with high-risk and /or metastatic prostate cancer care coordination through patient navigation has become a critical aspect of their care as often multiple types of treatment are required to include options offered only by medical oncology. Through patient navigation, in a digitally connected medical community, men can also participate in clinical trials either within Maine or with regional cancer center partners.

Though prostate cancer can be a daunting diagnosis, access to information and support, as well as care coordination, are powerful allies for the management of this disease. Through continued collaboration between patient and provider care groups, we can continue to educate and support men and their families, and ultimately to reduce the morbidity and mortality associated with prostate cancer in Maine.

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If you found this informative, please pass it along to others who might find the information of benefit. If you wish to be deleted from our contact list or if you know of someone who would like to receive this newsletter, please contact me at mjervin@roadrunner.com.

This newsletter is provided by the **Maine Coalition to Fight Prostate Cancer**, a statewide non-profit group dedicated to ending the "devastating impact of prostate cancer on men, their loved ones, and the State of Maine." For additional information about this group, please visit our website at mcfpc.org.